

**MINUTES
of the
FOURTH MEETING
of the
DISABILITIES CONCERNS SUBCOMMITTEE
of the
LEGISLATIVE HEALTH AND HUMAN SERVICES COMMITTEE**

**November 24, 2015
State Capitol, Room 322
Santa Fe**

The fourth meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee was called to order on November 24, 2015 by Senator Nancy Rodriguez, chair, at 9:09 a.m. in Room 322 of the State Capitol in Santa Fe.

Present

Sen. Nancy Rodriguez, Chair
Rep. Miguel P. Garcia
Sen. Linda M. Lopez

Absent

Rep. Tim D. Lewis, Vice Chair
Sen. Craig W. Brandt

Advisory Members

Rep. Deborah A. Armstrong
Sen. Ted Barela
Sen. Gerald Ortiz y Pino

Rep. Nora Espinoza

Guest Legislators

Rep. James Roger Madalena
Rep. Howie C. Morales

Staff

Shawn Mathis, Staff Attorney, Legislative Council Service (LCS)
Michael Hely, Staff Attorney, LCS
Nancy Ellis, LCS
Diego Jimenez, LCS
Erin Bond, LCS

Minutes Approval

Because the committee will not meet again this year, the minutes for this meeting have not been officially approved by the committee.

Guests

The guest list is in the meeting file.

Handouts

Handouts and other written testimony are in the meeting file.

Tuesday, November 24

Welcome and Introductions

Senator Rodriguez welcomed those assembled and asked legislators and staff to introduce themselves. As this was the last meeting of the 2015 interim, Senator Rodriguez expressed appreciation to fellow legislators who served on the subcommittee and those who attended as guests.

House Memorial 9 (2015) Task Force Report

Anthony Cahill, M.D., director of the Disability and Health Policy Division, Center for Development and Disability, University of New Mexico (UNM) School of Medicine, described difficulties for children between the ages of 14 and 21 with chronic, long-term and serious health conditions as they transition from pediatric providers into the adult health care system. Dr. Cahill said the task force, led by his UNM center and assisted by a federal grant from the Health Resources and Services Administration (HRSA), met five times between January and August to discuss possible solutions to the complex problems facing nearly 70,000 New Mexicans. The prime criterion for the group's recommendations was feasibility. The task force included broad representation from state agencies, UNM Hospital and UNM School of Medicine, health and community professionals, managed care organizations (MCOs), stakeholders and self-advocates and it produced a comprehensive report of findings and recommendations (see handout), including the following recommendations:

- development of online training for health care providers with continuing education credits, including specific competencies for transitioning youth with special needs;
- provision of funding to the Administrative Office of the Courts to perform a gap analysis on resources and support services for families seeking guardianship and other legal approaches;
- support with per diem and travel expenses for family members of youth with special health care needs who serve on state committees;
- development of a health literacy program reflecting cultural and linguistic needs;
- development of policies to improve access to health care for immigrants;
- directing MCOs to reimburse providers for care coordination in transferring youth with special needs into the adult system;
- development of a formal plan by the Children's Cabinet for collaboration among service agencies and to map systems and services available for this population from each state agency;
- provision of a gap analysis to document the potential need for a complex care clinic at UNM;
- provision of plans to increase access to oral health care for special needs youth in transition; and

- a request to the Office of Superintendent of Insurance to require MCOs and private health plans to publish and distribute changes in their provider networks and a request to provider licensing entities to track provider continuity with place of service and the health plan.

In a discussion following the presentation, it was noted that several task force recommendations urged specific funding to various agencies (see handout), and a member suggested that some recommendations may need to be broken down into separate bills. The low rate of provider reimbursement for special-needs youth transition is a major barrier to service, and the 30-minute limitation on dental service for patients on Medicaid is detrimental to coordinated care and could be viewed as discriminatory. The need for expanded access to dental services and oral health care for this special population was discussed at length. The chair urged legislators to think creatively on how best to move forward with these recommendations.

Medicaid Managed Care Assessments for Community-Based Services

Cathy Geary, M.B.A., B.S.N., R.N., director, Healthcare Services, Molina Healthcare, described the home and community benefit (CB) package that all Centennial Care (CC) recipients who qualify are entitled to, in addition to their physical and behavioral health benefits. The CB is intended to provide an alternative to institutional care and is meant to supplement natural supports (family, friends, community churches and clubs), she said. New Mexico residents who are Medicaid-eligible and who are assessed as needing nursing facility level of care (NFLOC) can choose between agency-directed or self-directed CBs. If the individual selects the agency CB, a care plan is developed for needed services. With the self-directed CBs, a support broker provides education and helps with budget development for that member.

Mari Spaulding-Bynon, R.N., M.D., director of clinical and long-term care operations for Presbyterian Health Plan, said a health risk assessment is done for all members, but an in-home comprehensive needs assessment must be conducted in order for a member to be eligible for the CB. A functional assessment of NFLOC is followed by assessment for physical, behavioral, psychosocial, environmental and safety needs. These assessments are done in collaboration with the member and a provider (medical, support broker or other caregiver) and are followed by development of a care plan, along with goals and interventions. Any inpatient or outpatient circumstance can trigger another assessment and update of the care plan, which cannot exceed the annual average cost of nursing home care in New Mexico (\$58,584), adjusted by the state annually.

Kellie Hammett, UnitedHealthcare, said that after a comprehensive needs assessment has been conducted and a care plan developed, the MCO will look first at what resources are available. If a service requested by the member is denied, it can be appealed to the MCO, she said. If the MCO denies it again, the member can request a fair hearing. Notices are sent to the member with the determination and include information regarding the appeals process. Customized community supports are available only through the self-directed CB.

On questioning, panel presenters and subcommittee members discussed differences in the CB between urban and rural areas. Services are available in urban communities, but in rural areas, when a member's needs have been clearly identified, the services are often unavailable. Family members in rural areas represent a much higher percentage of caregivers. The cost of personal caregivers is between \$11.00 to \$14.60 per hour, the MCOs reported. Very few new MCO members come close to the annual cap on community benefit services. Molina reported that of 4,300 members receiving the CB, only 33 are at 80 percent or more of the cap. If the need can be documented and assessed, the member can go above the cap. A subcommittee member said that on numerous occasions, she has been told that recipients of the CB have to reduce personal care hours in order to obtain other needed services. Another subcommittee member felt that there may be training issues with the individuals doing the assessments and urged MCOs to focus on additional training for them.

Public Comment

Lindsay Sloan, disability advocate, along with advocate Daniel Eppman, provided subcommittee members with a history and awareness fact sheet. Ms. Sloan reviewed federal legislation affecting the rights of disabled individuals and provided copies of New Mexico's Senate Memorial 48 (2015), which encourages educators to support the goals of disability history and awareness instruction.

Rebecca Sherman, a support broker for individuals on self-directed CBs, expressed shock upon hearing that a member can request an additional budget, after many years of being told that the cap can never be exceeded and is not appealable. Ms. Sherman said she has it in writing from the MCOs that members must "reallocate" their budgets in order to get additional services. She cautioned that, during an assessment, MCO members are not always able to communicate that they have other needs.

Jim Jackson, executive director of Disability Rights New Mexico (DRNM), said it is the experience of his organization that the CB planning and budgeting process does not work as represented by the panelists. He finds it hard to believe that only 275 individuals out of 22,000 would need assisted living if they were being properly assessed, and only 34 of these would need day services. The statistics provided defy understanding if there has been a true assessment of persons needing NFLOC.

Tim Gardner, DRNM legal affairs director, contends that the \$58,584 cap set by the Human Services Department is not legal, but his organization has not litigated the issue because it never applies: some individuals got grandfathered in, and the new system does not cap anyone because expenditures never reach the cap. The assessment does not provide an array of services; it is a number of hours for one service (personal care or homemaker services), he asserted. Individuals can only appeal the one number, not denial of other services; if an individual does not get a denial, that individual has no basis for appeal.

Ollie Liddell is a traumatic brain injury survivor and has organizational and focus difficulties. He is currently on a self-directed CB but has more complaints with the federal system, which has left him thousands of dollars in debt and in an unhappy position of dependence.

Sandy Skaar, M.S.W., support broker and owner of Self-Directed Choices, LLC, provided a handout describing issues with inadequate CB budgets, especially with hours based on a personal care assessment that does not address behavioral and community needs. She also asserted that MCOs are not responsive to changes in health conditions and are not moving members to self-direction, and that their biased appeal process requires members to appeal their own assessments. Ms. Skaar also expressed alarm that key CC staff have departed and their positions are still vacant. She provided a letter from a client complaining about being denied mileage reimbursement when the nearest grocery store is 120 miles away round-trip.

Patricia Mabry, who lives in Moriarty, spoke about her family's experience with Huntington's disease, which has claimed her father and brother and will take her son's life before he makes it onto the list for the developmental disability waiver. There are more than 6,000 New Mexicans affected by Huntington's disease, a genetic neurodegenerative disease, and Ms. Mabry urged legislators to support benefits and services for affected individuals through the federal Huntington's Disease Parity Act of 2015.

Jennifer Roth, a support broker/consultant with Self-Directed Choices, LLC, described difficulties for clients whose budgets were cut for no apparent reason, caregivers whose checks will be late again because Xerox did not mark their forms for payment and a lack of visits by care coordinators in rural areas. She asked that legislators intervene to mandate a fair hearing process, establish a trigger for independent assessments outside the MCOs and mandate that the third-party processor (currently Xerox) be held accountable to standard operating procedures in a meaningful way. She asked, "Do we have a community benefit to save the state dollars or to help its citizens?"

Cindy Padilla spoke of environmental modifications, how the budget of \$5,000 is not enough to complete most projects and how the consumer cannot afford to pay the difference. Many needs, including psychosocial and transportation, are not being addressed. Utilization managers at the MCOs are the deniers, Ms. Padilla said, especially of any activity that could be considered fun. Community access was promised and then taken away.

Ed Keller, who has traumatic brain injury, said some things are not even a possibility. In the past he had someone to help him organize and do paperwork. Homemakers cannot do paperwork, but now he has a care coordinator and a budget broker who have helped him.

Barbara Allen is caregiver for her 92-year-old father and has a brain injury herself. She came to speak up for those who work so hard as caregivers for disabled people. Ms. Allen, too, has experienced difficulty with payment from Xerox. She does not have access to a computer to

prepare time sheets for her father's other caregivers, and Xerox does not inform her if her time sheets are not accepted. Xerox needs to pay caregivers, she said.

Ken Collins is a program manager at San Juan Center for Independent Living in Gallup and also has a brain injury. Mr. Collins spoke of the need for training of MCO assessors and coordinators, who seem to choose a medical model over a social model, and of a need for more awareness of the independent living movement. More coordination and collaboration with MCOs are needed to improve member services.

Jill Kennon was formerly on Mi Via and assumed there would be a smooth transition to CC, but it took a year and a half. She is in total agreement with Mr. Jackson and Mr. Gardner from DRNM about inadequate assessments and MCO insistence on "home care". Ms. Kennon said she needs more direct support and that she does not want to be trapped in her home. The CB program was not meant to replicate a nursing home, she said. Assessments are not capturing all the needs; they are focused only on home care.

Report on Federal Legislation for Potential PACE Pilot for Persons with Disabilities

Beverly Dahan is vice president of government and legislative affairs for InnovAge, a nonprofit organization based in Denver that operates Program of All-Inclusive Care for the Elderly (PACE) programs in Colorado, New Mexico and California that serve over 24,000 frail elders. With this model, an interdisciplinary team provides all care at a PACE center for participants who have complex chronic conditions, helping them to maintain independence in their homes for as long as possible. The capitated rate paid to PACE providers has been shown to save up to 65 percent for Medicare in the last six months of an individual's life. On November 4, 2015, President Barack Obama signed U.S. Senate Bill 1362, allowing pilot programs of PACE for younger disabled adults (ages 18 through 54). The Centers for Medicare and Medicaid Services (CMS) will issue a request for proposals (RFP) to states for pilot programs, although the time line and parameters for this are still unknown. In March, the National PACE Association held a meeting to explore development of a care model that would adapt PACE to the needs of individuals with disabilities; details are included in a summary of those discussions (see handout).

PACE for a developmentally disabled population would look very different from the current model, Ms. Dahan said, adding that the size and makeup of the disabled population to be served is not yet known. A subcommittee member noted that it was a demonstration project that started PACE in New Mexico. Questioned about a time line for a possible pilot, Ms. Dahan has no idea how long it will take for the CMS to issue an RFP. It took about 26 years to establish PACE originally, she said, so lightning speed would be sometime next year.

End of Interim Report from Legislative Staff

Ms. Mathis provided a summary of the activities and topics addressed by the subcommittee during the 2015 interim (see handout) in four days of meetings with 40 presenters/panelists covering 16 topics. The handout also included copies of eight pieces of legislation that have been recommended by the subcommittee to the Legislative Health and

Human Services Committee for the 2016 legislative session. Senator Rodriguez thanked Ms. Mathis and other staff members of the LCS for their assistance.

Adjournment

There being no more business before the subcommittee, the meeting was adjourned at 2:40 p.m.